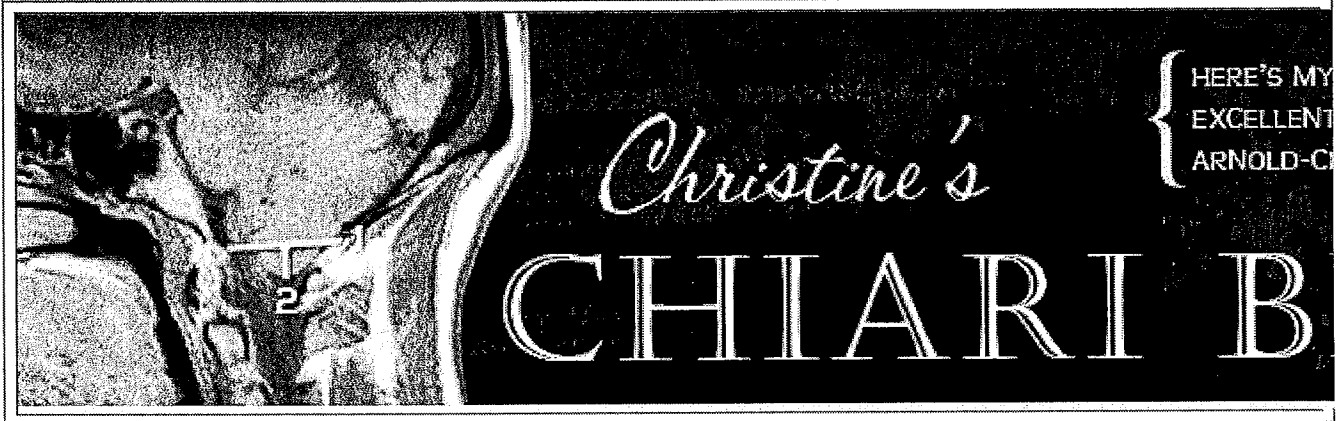


Exhibit A

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TUESDAY, SEPTEMBER 9, 2008

My Story

About 5 years ago I started having terrible headaches whenever I would lie down at night. I would wake up at 3:00 or 4:00 in the morning and toss and turn trying to find a comfortable way to sleep. The pain felt like pressure in my face behind my cheeks or eyes. My family doctor treated me for sinus infections several times, which I'm now certain I didn't have.

I had been seeing a neurologist for several years because I have a history of migraine headaches. The first time I complained of the nighttime headaches he did not think they were important. When I continued to complain about them 12 months later, he ordered an MRI. It showed that my cerebellum was herniated through the bottom of my skull into my spinal canal. He said this was a rare condition called an Arnold-Chiari Malformation. He quickly added, "Don't worry, we won't do surgery right away. We can try different medications to help deal with the pain." I think he was trying to make me feel better by this statement, but it had the opposite effect. Over the next two years he tried many different drugs that caused me to gain weight, fall asleep in the middle of the day and generally feel bad, but did nothing to relieve the pain. In fact, it was getting worse and I was getting little or no sleep at night.

My main goal is to turn my blog into a resource library of links to information about Arnold-Chiari Malformation. Subjects I have researched so far are listed below by date. You can also find my personal story starting at the very beginning of my blog.

ABOUT ME



CHRISTINE FROM WI
UNITED STATES

About 5 years ago I
started having

headaches when I would lie down that mysteriously disappeared when I sat up. An MRI determined I had a neurological disorder called a Chiari Malformation. I tried many different prescription medications that did nothing for my pain before I was referred to a neurosurgeon. Two surgeries later I ended up experiencing the worst pain imaginable, wondering if I was going to live or die. I was hospitalized for 14 weeks due to complications. Now, after my 3rd surgery, I am permanently disabled, suffering from chronic daily pain and more

I was getting very worried so I found a new neurologist for a second opinion. Although he thought surgery would be my only hope of relief, he wanted me to try one more drug first. He prescribed Topamax starting with 25 mg a day and slowly working it up to 200 mg a day. It did nothing for the nighttime headaches, but dramatically reduced my migraines. However, it gave me terrible cognitive side effects. For example, I could not figure out how to read a clock with hands on it, how to dial a long-distance telephone number, or how to read the gas gage in my car (I ran out of gas twice). Since then my dosage has been weaned back down to 25 mg so I no longer have the side effects but still have some relief from the migraines.

Next my neurologist referred me to a local neurosurgeon. During our consultation, the surgeon seemed very confident that he could help me. He said if Chiari was causing my pain, then decompression surgery would certainly take it away. I asked how many of these surgeries he had done and he replied 50 or 60. I asked if he ever experienced any complications and he said he had a spinal fluid leak once, but fixed it during the surgery. Having no idea what that meant, and not realizing at the time that 50 or 60 surgeries over a 30 year career works out to only 2 or 3 surgeries a year, I went ahead and scheduled my surgery for May 25, 2006.

Decompression surgery involves removing a small section of bone in the back of the skull, which relieves pressure by giving the cerebellum more room. The covering of the brain, called the dura, is then opened, and a patch is sewn in place to enlarge the covering and also provide more room. The surgeon may also remove or cauterize a small portion of the cerebellum that is herniated. The operation takes about two to three hours, and recovery in the hospital usually requires two to four days.

I remember waking up from my surgery and having intense pain in my entire head. I had a button to press for an automatic dose of


Chiari symptoms then when I started. I started a Chiari blog in hopes of helping others avoid what I have been through. When I was diagnosed, I knew very little about my condition. I simply trusted my doctors to do what was best for me. I did not research Chiari until I started having life-threatening problems and was amazed at the wealth of information available. I have gathered some of those resources together in hope of helping others. Please don't hesitate to contact me if you have any questions or comments!
christineschultz@new.rr.com

[VIEW MY COMPLETE PROFILE](#)

RESOURCE LIBRARY

- 2009 (13)
- ▼ 2008 (11)
 - December (1)
 - November (3)
 - October (4)
 - ▼ September (3)
 - [My 3-D CT scan](#)
 - [My MRIs](#)
 - [My Story](#)

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morphine. I would wake up, press the button and pass back out again. When I was awake, I was extremely nauseous and vomited constantly. I was also having hallucinations. I remember seeing flies all over the walls, graffiti on my husband's pants and piles of red blankets on shelves that were not really there. The nurses said the hallucinations were probably caused from all the morphine.

Several days after my surgery a nurse noticed I was leaking spinal fluid from my incision so I was given a lumbar drain for 3 days. (This is like a spinal tap that stays in your back to help regulate spinal fluid levels.) I had to lie on my side and not sit or stand up during the entire time. The leak persisted, so on June 10th the surgeon performed another operation to try and fix the source of the leak. When it was over he told me that the patch he put on my dura had a hole in it so he stitched it up and covered it with glue.

At some point I contracted bacterial spinal meningitis and was given antibiotics for 10 days. They told me the antibiotic was so powerful it would destroy my veins if they put it in my IV, so they had to put a special tube in my arm to deliver the medicine right over my heart. (I believe it was called a picc line.) At the end of 10 days no one tested me to make sure the meningitis was gone - they just assumed I was ok and sent me home.

I returned to the emergency room 2 days later with the worst headache of my life. I rated it a 15 on the 1-10 pain scale. I was given an IV and a button to press to deliver the drug Dilaudid. I remember lying in the fetal position wishing someone would kill me because my head hurt so badly. After I had hit my button 5 or 6 times I finally started to feel some relief. The pain was still there, but it was almost like it was a separate thing from me. It's hard to explain, but I finally felt like I had some control over the pain and I wasn't so terrified. Suddenly I realized a nurse was shaking me and telling me to wake up because I was only breathing 4 times a minute. They had set my Dilaudid pump dosage too high and I had

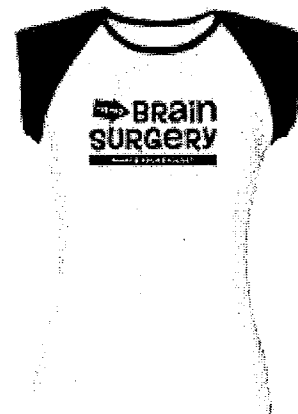
GOOD WEBSITES

ASAP - American Syringomyelia Alliance Project
WACMA - World Arnold-Chiari Malformation Assoc.
Conquer Chiari
Chiari Connection International
Chiari & Syringomyelia Foundation
Column of Hope
Chiari People
Wishes and Rainbows

INTERESTING LINKS

Researchers Find Way to Measure Pain
Boy Does Not Sleep for 3 Years
A Letter From Your Brain
Dogs with Syringomyelia
Cerebrospinal Fluid Facts
MRI and CSF Flow Study Example

CHIARI T-SHIRTS & MORE!



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accidentally taken too much. The nurse said she had to do something to reverse the effects of the Diluaded so I should prepare myself for the pain to come back. I cried and begged her not to do this and in the end she didn't but stayed with me until I was breathing normally again.

Of course they soon discovered I was still infected with spinal meningitis. I was given another picc line and 6 more weeks of antibiotics. I was continuously nauseous and could not keep any food down for almost 10 weeks. I had no appetite, everything tasted like cardboard, and whatever I did manage to eat just came right back up as soon as I swallowed it.

The second operation to fix my dura leak was unsuccessful. I still had spinal fluid building up in a cyst under my skin at the back of my head. (This is called a pseudomeningocele.) My surgeon tried aspirating the fluid out with a large needle and syringe five different times, but decided to stop since it just kept coming back. Plus I think he was afraid of giving me another infection.

When I first learned about the pseudomeningocele, my surgeon talked about putting in a shunt to drain the built up fluid. When I asked him about it later, he just kept saying it was no longer an option. After four and half months in the hospital, my doctors said there was nothing more they could do for me. My husband started searching for a new doctor or hospital to transfer me to, but it was not an easy task. Most doctors were reluctant or simply refused to get involved with my case.

We were finally able to arrange my transfer to the University of Madison-Wisconsin hospital for a second opinion. It was a complete waste of our time. Their neurosurgeon actually said to me, "I do not want to 'muck around' in your head right now." I stayed at their hospital for 4 days of observation and was sent home.

FACEBOOK BADGE

Christine Schultz's Profile



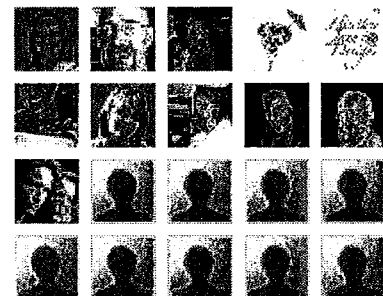
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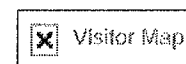
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So I returned home feeling totally abandoned by my doctors. I was given no instructions on how to take care of myself or try and regain my strength. I had been bedridden for 14 weeks and had lost almost 40 lbs. There were no orders for any kind of physical therapy. I was weak and any amount of effort made my head pound and left me nauseous and shaky. Taking a shower wiped me out for the rest of the day.

On top of the pain of healing from two major brain surgeries, I now had more Chiari symptoms than I started out with. I still had pain in my face when I would lie down, plus I now had pain at the back of my head whenever I would cough, sneeze, strain, bend over, sit down or step down too hard. I was afraid to move. I also had pins and needles pain and weakness in my arms and legs and bouts of vertigo.

My husband and I started researching Chiari on the Internet and were amazed by the information we found. We were especially excited to discover The Chiari Institute in New York. Their website boasts that in 2003 alone, they performed 292 surgical procedures - more than half of which were referred for re-operation because of failed Chiari surgery elsewhere. (In 2007 TCI performed almost 700 Chiari related surgeries.)

I had my initial consultation at TCI in May 2007. It was a two-day appointment. The first day I met with a neurologist for an exam and had MRI, CT and X-rays taken. On the second day I met with neurosurgeon, Dr. Bolognese.

Dr Bolgnese went over all my test results and explained how my original decompression surgery had failed and told me I needed to have it redone. I was not surprised by this. He said my body was rejecting my

dura patch (it was made out of bovine material) so that is why it was leaking. It needed to be replaced with my own material from

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under my scalp. He also showed me that the hole cut in my skull was not centered, it was off to the right side, so it needed to be fixed too. (I have posted my MRI and CT scans here on my blog if you would like to see them.)

Next, Dr. Bolognese told me I had a second neurological condition called a tethered spinal cord. I was shocked by this information. I knew that they tested me for it because it is a rare, but related condition, but I had no tethered cord symptoms (they include lower back and leg pain, incontinence and sexual dysfunction). Dr. Bolognese said the tethered cord was evident on my MRI and that I needed surgery to correct it or it would cause problems in the near future.

I had my spinal cord de-tethering surgery on July 13, 2007. Because of my previous experience, I was bound and determined to get out of the hospital as soon as possible! I was up and walking by day three and checked out on day four. The pain was pretty bad while I was in the hospital - I had the dreaded Dilauded pump again - but it was bearable once I got home.

When I healed from the surgery I noticed that my head was feeling a little better. I was having less pain when I moved suddenly or jarred myself. Before, I was afraid to even get the hiccups, because each one would cause a huge burst of pain at the back of my head. Now it was not as bad, but I couldn't figure out why.

I returned to TCI in October for a checkup. I saw a neurologist, Dr. Chen. He took out my MRI scans from earlier that day and said, "Look, your pseudomeningocele is gone!" My dura leak was completely healed. I was so excited I didn't even think to ask him why. I was just so happy the leak was gone because I assumed it meant I didn't need any more surgery. I told him that I was feeling a little better, but I still had pain when I would lie down and especially with any kind of activity. He said my brain had moved a

lot after my surgery. It may need some time to heal and re-route some nerves. In my excitement I asked Dr. Chen to sign a paper releasing me to return to work. I just wanted to be done with doctors and hospitals and get my life back to normal.

I went back to work in November. (I was a graphic artist and worked for our hometown newspaper.) It was very strange returning to work, because in my mind, I was only supposed to be gone for 6 weeks. For some reason I was having a hard time coping with the fact that it had actually been over 18 months. So much had changed in that time. Also, I didn't get my same job back. Of course they couldn't hold my spot forever, so I ended up having to take a different position. It was actually easier than my old job (not as stressful). Overall, I was very relieved be working again.

The very first day I went back to work I was sorry. I had terrible pain in my face and was extremely nauseous after only an hour at the computer. But that very same week I found out I had to have gallbladder surgery. I had been having sharp pains under my ribcage off and on for the last year that doctors attributed to stress. It turns out that if you don't eat for long periods of time the bile in your gallbladder can crystallize and turn into gallstones. So I reluctantly agreed to more surgery and told myself that after my gallbladder was out, I would feel much better.

While I was recovering from that operation, I received a phone call from the hospital lab. They had found something suspicious on my last mammogram. I had to go in and have a sonogram of my left breast. During the sonogram, the technician called in a radiologist who said he was "pretty certain" it was cancer. He did a biopsy right then and there. Thankfully, it turned out to be benign. But they wanted to take the lump out anyway because they said it was the type of tissue that cancer likes to grow next to. So, the week after Christmas I had surgery to remove it.

During all this time, I was having a terrible time at work. I wasn't getting any sleep because of the pressure and pain in my head. I spent most nights trying to sleep upright in a chair, but that wasn't very restful either. Working on the computer was giving me tremendous headaches and unrelenting nausea. I had terrible pins and needles sensation in my legs and feet and my fingers kept going numb. Every single ounce of my energy went into getting through another day of work. I believe I used up all my sick time in my first 6 weeks. I kept telling myself, if I can just get through this week, things would start to get better. But they just kept getting worse.

Meanwhile, I was useless at home. I completely stopped cooking and cleaning. I did not leave the house to even buy groceries. My daughter would come home from school and start looking through the cupboards and there would be nothing for her to eat. Even taking care of myself was getting impossible. Some days I was in too much pain or too exhausted to wash my clothes or take a shower.

Then, one day, my boss called me into her office. I was sure that she was going to fire me. She said she was really worried about me because I looked like hell. That's when it finally dawned on me that I was pushing myself too hard. I contacted TCI and told them about my increasing symptoms. Dr. Bolognese replied by simply stating the obvious: I still needed to have decompression revision surgery. He had told me that at the start but I guess I had been in denial... wishing I could skip the second part and just get back to my normal life! He wrote a letter stating that I should not be working, ordered more MRI scans, and scheduled my surgery for May 22, 2008.


I had a phone consultation with Dr. Bolognese in April so I could ask questions about my upcoming surgery. He reviewed my new MRIs and gave me some unexpected news. After my tethered cord surgery, my spinal cord moved up and my cerebellum moved over and stuck to my dura with scar tissue. This is what stopped my dura leak. However, the scar tissue "went a little crazy" and is pulling

on and stretching my brainstem. I have no flow of spinal fluid behind my brain anymore. He said the tonsils of my cerebellum are still herniated. This - combined with blocked spinal fluid flow and damage to my cerebellum and brainstem - are what's causing the symptoms I am having now.

Unfortunately, Dr. Bolgnese said it would be too risky to try and detach my brain from my dura now. So I'm afraid there is nothing else he can do to help me. He said even if he could detach my cerebellum, it would be so nicked up and irritated it would eventually just re-attach itself with more scar tissue. He gave me two examples of patients with similar situations who had surgery and ended up right back where they started in 6 months. He said if it were him, he would not risk it.

I guess I should be relieved that I'm not going to have any more brain surgery. But I am really disappointed that Dr. Bolognese can't help me. He said he doesn't think my cerebellum and brainstem will change much from the way they are right now. He doesn't expect my symptoms to get any worse if I adjust my lifestyle to keep from aggravating things. But my symptoms probably won't ever improve either. So now I am just trying to learn how to cope with them.

My greatest wish is to somehow spare someone else from going through what I have. My best advice is this: Never blindly trust a doctor to know what is best for you. Educate yourself. Research your treatment options. Especially if you are diagnosed with something you have never heard of! Find a doctor who specializes in exactly what you are dealing with. You need someone with loads of experience. Don't be someone's guinea pig. Don't be afraid to ask lots and lots of questions. If you don't like the answers, keep looking. It will be worth it. YOU are worth it.

POSTED BY CHRISTINE FROM WI AT 12:41 PM 

LABELS: MY STORY. CHIARI